RATIONAL
Idiopathic pulmonary fibrosis (IPF) is associated with progressive worsening of pulmonary function (reflected as decline of forced vital capacity (FVC)) with serious limitation of physical activities and quality of life.

The patientMpower platform is an electronic health journal developed for IPF. It enables patients to record medication adherence, activity level, objective (e.g., FVC and subjective (e.g., dyspnea) measurements & health outcomes, by using the app on the patient’s mobile phone/device. FVC can be recorded weekly or every 2 weeks, allowing longitudinal collection of patient-measured FVC.

METHODS
Prospective, pilot scale, open label, single-centre, usual care-controlled, fixed order crossover observational study (8 weeks) (www.clinicaltrials.gov NCT03104322). Planned sample size = 8.

Study Design:

<table>
<thead>
<tr>
<th>Baseline</th>
<th>Week 8</th>
<th>Week 16</th>
</tr>
</thead>
<tbody>
<tr>
<td>patientMpower usual care</td>
<td>crossover</td>
<td>usual care</td>
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</tbody>
</table>

Start
Entry criteria: Diagnosis of IPF (multidisciplinary team confirmed), age ≥ 40, owns smartphone/tablet, written informed consent, no recent exacerbation/addition of antifibrotic. No changes to usual healthcare.


Measurements: Patients asked to use pM daily for 8 weeks [period 1]. FVC (best 3), dyspnea (Medical Research Council (mRC), medication adherence, PROM (1-6 scale). Patient (1-point) questionnaire) & healthcare professional (5-point questionnaire) opinion sought at week 8. Followed by 8 weeks usual care (period 2). FVC, mRC, 6-minute walking distance, PROM assessed at clinic at baseline, week 8 & week 16.

Dispositions of patients:
Eight patients expressed interest; 7 participated and completed spirometry data. Only 2 (29%) recorded PROM or dyspnea data on pM. 4 patients (57%) provided opinion on utility and acceptability.

RESULTS
Baseline demographics:

- Total patients (N): 4
- Male/female: 7/3
- Age (mean, range): 69 (57-79)
- Clinic observed FVC (L); mean, range): 2.91 (range 2.49-3.37)
- Clinic observed predicted FVC (L); mean, range): 75 (28-105)
- 6-minute walking distance (m, mean, range): 560 (230-675)
- Clinic observed mRC (score range of patient): 3 (2)
- Patient reported mRC (L); mean, range): 2.64 (range 1.15-3.24)
- Time above mRC (L): 2.4 (range 0.9 to 5.6)
- Antifibrotic therapy (number of patients): 1 (1 patient)

User feedback:
- 4 patients (57%) provided feedback at median 78 days (range 78-82). Responses were mostly positive (illustrated in four charts below). We wanted to continue using pM after the study and would recommend it to others. 2-3 responses reported difficulty using pM and felt it was not user friendly for the patient.
- Patient stopped using pM after 5 days and expressed negative opinions.

PROM (hospital measured) Q1: How have breathing difficulties affected your quality of life?
- 2.64 (range 1.15-3.24) people experienced change from baseline.

PROM responses (at clinic):
- review change in the quality of life from total score (range 0-100)
- Patient reporting quality of life is "good" at baseline and "fair" at week 8.

CONCLUSIONS
Patients with established IPF attending a specialist ID clinic are willing and able to use an electronic health journal to record data, symptoms and outcomes. Age is not a barrier to this approach.

The patientMpower platform (pM) is acceptable and feasible to some patients with IPF at least 4.7/10 in this study and all who provided a response wished to continue using pM after the study and would recommend it to other patients with the same lung condition. However, one other patient stopped using pM after 5 days and expressed negative opinions.

Patients with IPF appear willing to record home spirometry regularly without prompting which suggests they are interested in monitoring their lung function. There was close agreement between home spirometry and clinic observed FVC values by week 8.

The relevance to patients of recording medication adherence and symptom scores (e.g., dyspnea, PROM) on pM is clear. Consideration should be given to additional use of prompts to improve frequency of recording these measures and broaden the information collected.

This small study suggests that the patientMpower platform is feasible and acceptable to some patients with IPF to use as an electronic health journal to record home spirometry over an 8 week observation period as part of expert care at a specialist ID clinic. This approach may provide a mechanism for early identification of exacerbations or accelerated decline in lung function which is not important in future management.

We would like to thank all the patients who took part in this study.

Commercial support: remission financial interests. Funded by the patientMpower Ltd and Health Service Executive of Ireland Quality Innovation Contract (grant 137:3-016). C. Edwards & E. Costelloe are employees of stakeholders of patientMpower Ltd.

REFERENCES
- Saolta University Hospital, Galway University Hospital, Royal Brompton Hospital, The Digital Depot, Thomas Street, Dublin 8, Ireland. Loyal Internationals, Sydney, London, 1543 UK.

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Patient-reported Monitoring of Symptoms and Spirometry via the patientMpower Platform in Idiopathic Pulmonary Fibrosis

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